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TAGS: [UNESCO](#) [TBIO](#) [US](#) [KSCI](#) [FR](#)
SUBJECT: USUNESCO: 13th SESSION OF THE INTERNATIONAL BIOETHICS
COMMITTEES CHARTS FUTURE COURSE ON THE TWO WORKING GROUP REPORTS:
SOCIAL RESPONSIBILITY AND HEALTH AND CONSENT

¶1. Summary: The 13th session of the International Bioethics Committee (IBC) examined the preliminary reports of its working groups on social responsibility and health and on consent. During the debate on social responsibility and health, IBC members reiterated their independence from UNESCO itself and member states. The debate on consent focused on patient autonomy, the different types of consent, and regulation of the flow of information related to a patient's right to know. A UNESCO official urged that the reports and subsequent debate adhere to the principles and language contained within the Declaration itself. End Summary.

¶2. Following the adoption of the Universal Declaration on Bioethics and Human Rights in 2005, the International Bioethics Committee (IBC), at its 12th session in Tokyo in December 2005, decided to set up two commissions in order to prepare reports concerning two principles stated in the Declaration: one on consent (Articles 6 and 7) and one on social responsibility and health (Article 14). This session of the IBC sought to assess and debate the preliminary reports of the two working groups.

¶3. At the opening, Henk ten Have, Director of the Division of the Ethics of Science and Technology, gave a detailed account of activities undertaken by UNESCO for the dissemination, the promotion, the application, and the elaboration of the principles of the Universal Declaration on Bioethics and Human Rights.

Social Responsibility and Health

¶4. Director-General Matsuura stressed that the IBC should adopt a different approach than other international forums such as the World Health Organization. Nouzha Guessous-Idrissi (from Morocco) recalled that the IBC's role is not to replicate work already done by other organizations, but to refocus and redefine the debate from the point of view of bioethics. She stressed the importance of Article 14 of the Declaration as it acts as a synthesis of the Declaration itself, as well as parts of other existing declarations, for example Article

27 of the Universal Declaration on Human Rights. An invited expert, William Schabas from the Irish Centre for Human Rights, linked the debate on Social Responsibility to Article 27 of the Universal Declaration on Human Rights. He stated that if there is a right to benefit, then people who have that right also have a right to determine the direction of research. While holding up a photo of Eleanor Roosevelt, he made a gratuitous remark against the United States by saying that the U.S. was "at one time" a leader in the development of human rights. Gabriel d'Empaire (from Venezuela), Vice-Chairperson of the IBC, called for specific levels of responsibility, a precise definition of the concept of "highest attainable standard of health" with criteria for the realization of this goal, and rational selection of necessary medicine.

¶15. Numerous IBC members complained that the developing world has not received the benefits of health care technology. Donald Evans (from New Zealand) stated that the world needs international responsibility, declaring that developed countries exploit developing countries. Gamal Ibrahim Abou Serour (from Egypt) claimed that governments in developing countries are complicit in the brain drain. Claude Huriet (from France) said that improving health in developing countries does not come from innovation and technology. He insisted that basic needs can and shall be satisfied without access to the latest technology. Prakash Narain Tandon (from India) asserted that the objective of the IBC is to reduce gaps between the rich and poor countries and within countries.

¶16. Jeanine-Anne Stiennon (from Belgium) said that governments cannot provide health care for their entire populations. For example, in Europe, citizens over the age of 70 do not receive the cancer medications and other forms of health care promised their government. Prakash Narain Tandon asserted that inequities exist in the United States: 35 million people go hungry and 30 million people have to pay for their health care. He said that it would be a disaster if health care became part of the world economy as the World Bank has suggested. Kwang-ho Meng (from South Korea) insisted that bad lifestyles are responsible for fifty percent of today's health problems. He said that fighting against malnutrition is one of the best ways to improve world health.

¶17. Some IBC members linked the debate on bioethics to the debate on intellectual property rights. Toivo Maimets (from Estonia) argued that the world needs public financing for the development of important drugs with no patent protection. Jean Martin (from Switzerland) argued against intellectual property rights and also suggested creating a convention against smoking. William Schabas argued that the inability to obtain access to needed medicine constitutes a human rights violation.

¶18. Arguing that inequalities in health care are immoral and unethical, Jean Martin insisted that the IBC take advantage of its independence to display courage in the drafting of its documents and recommendations, even if it is sometimes politically and diplomatically incorrect. Marwan Hamade (from Lebanon) argued that the IBC should limit its objectives specifically to what is in Article 14 and that the role of the working group report should be to give new rules of engagement on social responsibility. All members agreed that the report should convince stakeholders at all levels, to adopt socially responsible behavior. Jeanine-Anne Stiennon suggested that the word 'should' be changed to read 'shall' in Article 14 of the Declaration.

Consent

¶19. IBC Members discussed autonomy and consent and the problem posed for uninformed patients.

¶10. Members discussed the problem of paternalism as it affects the doctor-patient relationship. Members said that paternalism should be avoided; however, Ole Johannes Hartling (from Denmark) noted that in some situations, i.e. for unconscious patients, paternalism is occasionally necessary. In paragraph 26 of the report, it is stated that the relationship between the doctor and the patient "cannot be equal to equal." Gabriel d'Empaire commented on this point, saying that this should not be presented as fact rather than the relationship depends on circumstances.

¶11. Ching-li Hu (from China) argued that cultural differences should be taken into account. He explained that in China, medical decisions are often made by the family as a whole. Sissel Rogne (from Norway) objected to this idea of putting emphasis on the family decision making model due to the fact that this touches upon gender issues related to patient autonomy. Mr. ten Have countered that cultural differences do exist, but that this cannot be used to say that principles of consent do not apply. He insisted that in any discussion of an exception to informed consent, the exception must be made in relation to principles found elsewhere in the Declaration.

¶12. Many IBC members brought up the difference between consent at the clinical treatment level and at the research level. Members repeatedly asked for greater elaboration on what consent is in each scenario. Mr. ten Have argued that this question must be clarified by referring to the terms used within the Declaration itself.

¶13. Concerning secondary usage of biological samples for scientific research, paragraph 79 of the draft report states that it is "not acceptable" to obtain "overall prior consent." Ephrat Levy-Lahad (from Israel) expressed concern about this language as many biobanks currently obtain this kind of consent when dealing with the secondary usage of biological samples in scientific research. A Canadian observer intervened on this point to comment that in Canada and the U.S., the use of samples for secondary research is subject to ethics committee reviews and that secondary consent can be waived.

¶14. Debating on patients' right to know/not to know, Claude Huriet (from France) and a Tunisian observer commented on the need for the report to address the role of the media. Both delegates said that much of the information available online is not accurate. The two delegates stressed the adverse effects that incorrect information can have on informed consent and the doctor-patient relationship.

¶15. In paragraph 31 of the draft report, the "right not to know" is mentioned. Several IBC members requested a more in-depth exploration of this topic within the report. However, ten Have reminded members that "the right not to know" is not mentioned within the Declaration itself. He maintained that there must be a correlation between the report and the Declaration.

¶16. Observers from the Ivory Coast and Tunisia requested that the report make a distinction between a legitimate representative and a legal representative in situations where a patient may be unable to give consent. Fawaz Saleh (from Syria) remarked that the question of legitimate and legal representatives is something that originates in domestic law of a state. In addition, he argued that a legal representative is always a legitimate representative, but a legitimate representative is not always a legal representative.

¶17. COMMENT: IBC members (36) are appointed by the DG as "independent experts" to make recommendations and give advice. (Edmund Pellegrino, Chairman of the President's Council on Bioethics, is a member of the IBC but was not able to attend this meeting.) It is one of several such bodies (COMEST is another, particularly problematic one). Pronouncements of IBC may sound to the outside world as if they represent UNESCO views. In addition, it can be used to start momentum for and influence the direction of normative instruments. In 2005, the IBC presented a draft Bioethics Declaration to Member States that was largely unsatisfactory to Member States (for different reasons), and had to be rewritten; but because the IBC draft was the starting point, the process was difficult and constrained. The existence of these bodies of "independent experts" raises serious governance questions; the USG may want to consider whether to challenge the creation and continuation of these bodies. END COMMENT.
OLIVER